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Research Article

Profile of palliative care by home care service in Divinópolis-MG

Perfil dos atendimentos em cuidados paliativos pelo Serviço de Atenção Domiciliar de Divinópolis-MG

Perfil de cuidados paliativos por el Servicio de Atención Domiciliaria de Divinópolis-MG

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Abstract

Introduction: Palliative care (PC) is aimed at controlling physical, social, spiritual and emotional symptoms. In Brazil, there is currently a scenario of accumulation of terminally ill patients, which contributes to the country being considered the 3rd worst to die in. Dehospitalization, with patients attended to by a home care service (HCS), is seen as a way to improve patients' quality of life and reduce costs for the national health system. **Objective:** To identify the profile of patients in PC assisted by the HCS of Divinópolis-MG, as well as the service's interventions and their effectiveness. **Methods:** Descriptive study carried out from the retrospective analysis of medical records of patients who were discharged from the HCS of Divinópolis-MG between 2020-2021, with quantitative collection of the following data: sex, age, home address, responsible multidisciplinary home care team (EMAD), type of illness, interventions of HCS teams, effectiveness of HCS interventions, symptoms presented, effectiveness of symptom control and reason for discharge from the service. **Results:** Data were collected from 72 medical records, from which, an average age of 67 years was found, with a predominance of female patients and neurodegenerative diseases. Regarding the symptoms presented in the medical records, 54 were treated effectively and 23 ineffectively, and 22 were not treated. Discharges for symptom control accounted for 43% of the total. **Conclusion:** The HCS's ability to adequately manage patients eligible for PC is highlighted, to control symptoms — physical, social, psychological and family — , contributing to the improvement of the quality of life of the patient and their social circle.

Keywords: Palliative care; Home care services; Health profile.

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Resumo

Introdução: Os cuidados paliativos são voltados para o controle de sintomas físicos, sociais, espirituais e emocionais. Atualmente, há no Brasil um cenário de acúmulo de pacientes em situação de terminalidade, o que contribui para que o país seja apontado como o 3º pior lugar para se morrer. A desospitalização, com cuidado prestado pela Atenção Domiciliar, é apontada como uma forma de aprimorar a qualidade de vida dos pacientes e reduzir os custos para o Sistema de Saúde. **Objetivo:** Identificar o perfil dos pacientes em cuidados paliativos assistidos pelo Serviço de Atenção Domiciliar de Divinópolis-MG, bem como as intervenções realizadas e sua efetividade. **Métodos:** Estudo de caráter descritivo, realizado a partir da análise retrospectiva de prontuários de pacientes que receberam alta do Serviço de Atenção Domiciliar de Divinópolis-MG entre 2020 e 2021, com coleta quantitativa dos seguintes dados: sexo, idade, endereço de moradia, equipe multiprofissional de atenção domiciliar responsável pelo atendimento, tipo de enfermidade, intervenções realizadas pelas equipes do Serviço de Atenção Domiciliar, efetividade das intervenções feitas pelas equipes do Serviço de Atenção Domiciliar, sintomas apresentados, eficácia do controle sintomático e razão da alta do serviço. **Resultados:** Foram coletados os dados de 72 prontuários; a partir disso, constatou-se uma faixa etária média de 67,38 anos, com predomínio de atendimentos a pacientes do sexo feminino e de acometimento por enfermidades neurodegenerativas. Em relação aos sintomas apresentados nos prontuários, 54 foram tratados de forma eficaz, 23 de forma ineficaz e 22 não foram tratados. As altas por controle sintomático representaram 43,04% do total. **Conclusões:** Ressalta-se a capacidade do Serviço de Atenção Domiciliar de manejar adequadamente os pacientes elegíveis para os cuidados paliativos, a fim de controlar sintomas — físicos, sociais, psicológicos e familiares —, contribuindo para a melhoria da qualidade de vida do paciente e de seu círculo social.

Palavras-chave: Cuidados paliativos; Serviços de assistência domiciliar; Perfil de saúde.

Resumen

Introducción: Los cuidados paliativos (CP) están dirigidos a controlar los síntomas físicos, sociales, espirituales y emocionales. Actualmente, en Brasil, hay un escenario de acumulación de enfermos terminales, lo que contribuye a que el país sea señalado como el 3º peor en morir. La deshospitalización, con atención domiciliaria, es vista como una forma de mejorar la calidad de vida de los pacientes y reducir costos para el Sistema de Salud. **Objetivo:** Identificar el perfil de los pacientes en CP asistidos por SAD en Divinópolis-MG , así como las intervenciones realizadas y su efectividad. **Métodos:** Estudio descriptivo, realizado a partir del análisis retrospectivo de prontuarios de pacientes que fueron dados de alta del Servicio de Atención Domiciliaria (SAD) de Divinópolis-MG entre 2020-2021, con recolección cuantitativa de los siguientes datos: sexo, edad, domicilio de vivienda, EMAD responsable de la atención, tipo de enfermedad, intervenciones realizadas por los equipos SAD, efectividad de las intervenciones realizadas por los equipos SAD, síntomas presentados, efectividad del control sintomático y motivo de alta del servicio. **Resultados:** Se recogieron datos de 72 prontuarios, de los cuales se encontró una edad promedio de 67 años, con predominio de pacientes del sexo femenino y enfermedades neurodegenerativas. En cuanto a los síntomas presentados en las historias clínicas, 54 fueron tratados de manera efectiva, 23 de manera ineficaz y 22 no fueron tratados. Las altas por control sintomático representaron el 43% del total. **Conclusiones:** Se destaca la capacidad del SAD para manejar adecuadamente a los pacientes elegibles para CP, con el fin de controlar los síntomas -físicos, sociales, psicológicos y familiares-, contribuyendo a la mejora de la calidad de vida del paciente y su círculo social.

Palabras clave: Cuidados paliativos; Servicios de atención de salud a domicilio; Perfil de salud.

INTRODUCTION

The aim of palliative care (PC) is to improve the quality of life for patients and their families through the control of symptoms, not only physical but also social, spiritual and emotional.[1,2] According to the World Health Organization (WHO), pain relief and the mitigation of other manifestations are the principles of PC, thus making it possible to improve the quality of life of the user and their family circle, and, therefore, this therapeutic modality must be started early.[1]

In contrast to the expansion movement of PC in Brazil and around the world, the accumulation of terminally ill patients in hospitals persists, with these patients usually receiving inadequate assistance and the hospital unable to provide adequate care for this phase.[3] This is a context common throughout Brazil, contributing to it being considered the 3rd worst country to die in.[4] Furthermore, it is common for patients in the final stage of life to receive exacerbated, invasive and high-tech therapies.[3]

To change this scenario, we must expand our understanding of the role of health professionals beyond the rigid limits of cure, reaching the dimension of care.[3] To this end, it is essential that the demands of the patient, the family and their social circle, as well as the socioeconomic context, be known; it is noted that obtaining this information can be carried out in reference to the Family Health Strategy program. Therefore, it is necessary for PC to be included in primary health care, forming part of an integrated health network, as an instrument of person-centered care.[5-7] Its role linked to home care is highlighted by its work in symptom control, relief of suffering and improvement of quality of life and dignity for patients and families outside hospitals.[8,9]

Home care is directly related to dehospitalization, in addition to providing quicker hospital discharge, reducing costs and the occurrence of hospital infections, mitigating clinical complications, offering emotional support for the patient and their family and promoting autonomy of care for these patients.[10,11] Furthermore, home care promotes flexible schedules, variety in food and the possibility of leisure, strengthening the patient's autonomy and their sense of belonging.[11,12] Furthermore, it allows the family a greater perception of help, as they actively participate in the patient's care.[12,1]

Home care is regulated and defined by Ordinance No. 825 of April 25, 2016 as a type of health care characterized by actions to prevent and treat diseases, rehabilitation, palliation and health promotion — provided at home —, ensuring continuity of care.[14] In relation to PC in home care, teams must have cultural competence to work on values, communicate clearly, control symptoms, instruct caregivers and family members and enhance quality of life for the patient and family.[12]

Between 2013 and 2015, in Brazil, in PC provided by the Home Care Service (HCS), there was a predominance of male patients and, with the most common cancers being prostate cancer and breast cancer for male and female patients, respectively.[15] Furthermore, it is noteworthy that the majority of users eligible for PC throughout the country had cerebrovascular conditions.[16] Furthermore, it is noted that the majority of referrals for home care were made by the basic care unit.[15]

This study is justified due to the importance of establishing improvements in the care of patients eligible for PC, especially in Brazil where access to this care is limited,[3,4] resulting in psychological, social, biological suffering and, finally, mysthanasia and dysthanasia, contrary to the precepts established by the WHO.[5] Furthermore, there is a lack of studies dedicated to analyzing the profile of care provided by the HCS related to PC, resulting in a general lack of knowledge of the national care scenario in this modality. Considering the need to include PC in primary health care and home care per the WHO principles,[5] knowing the profile of care and patients in PC, especially those linked to the HCS, is a way of contributing to the evolution of this type of care in Brazil.

Therefore, the objective was to map and identify: the profile of patients assisted in PC by the HCS of Divinópolis-MG and the interventions of the team and their effectiveness. We thereby intended to contribute to the implementation and improvement of HCS in Brazil.

METHODS

This was a descriptive, quantitative study, carried out from the retrospective analysis of data from medical records provided by the Municipal Health Department of Divinópolis (SEMUSA), regarding patients in PC admitted by the HCS from July 2020 and who were discharged from the service by July 2021. To carry out this work, approval was obtained from the Research Ethics Committee of the Federal University of São João del-Rei, under CAAE 52595621.5.0000.5545, as well as a signed informed consent form for the use and handling of data by SEMUSA.

For data collection, all records of patients who were discharged from the HCS between July 2020 and July 2021 were analyzed, separating for complete reading the records of patients eligible for PC, with the inclusion criterion being the presence of conditions or life-threatening illnesses, using the NECPAL-BR as a guiding instrument.[17] From this selection, the following variables were collected, through a complete and careful reading of the medical records, according to the data extraction form, containing: identification number of the medical record; sex; age; home neighborhood; EMAD responsible for service; type(s) of illness(es); HCS interventions; symptoms presented and presence or absence of effectiveness of the intervention; and reason for discharge.

The patients' illnesses, as well as the effectiveness of the interventions of the team, were collected on basis of the description recorded by the health professionals, without the use of an instrument to qualify their effectiveness. Accordingly, the symptoms presented and the presence of pharmacological and non-pharmacological interventions aimed at controlling these symptoms present in the medical records were noted.

To define the presence or absence of directed therapy and its effectiveness, we established that: 1. those in which there is no therapy in the medical record directed at that symptom or set of symptoms will be considered untreated; 2. those in which there is therapy throughout the medical record directed at the symptom or set of symptoms will be considered as treated, being considered effective when there is a report of improvement and ineffective when there is no report of improvement or when there is a report of worsening of that symptom.

Accordingly, the information collected was entered into Excel software for tabulation and statistical processing, forming a structured database. Subsequently, univariate statistical analysis was carried out using the Statistical Package for the Social Sciences (SPSS) software, with recoding of the collected elements into numerical and dichotomous data.

RESULTS

Among the medical records studied, 72 were eligible for analysis. In this group, 47 consultations were carried out by EMAD 1 and 25 by EMAD 2. Regarding the profile of patients approached by the Divinópolis HCS, 25 were males and 47 females. For this population, the mean age was 67 years.

The diseases identified and recorded in the medical records by the HCS team were collected in accordance with what was set out in Table 1.

Table 1. Illnesses of patients eligible for palliative care through Home Care Service of Divinópolis-MG.

Illnesses	Number of patients	%
Renal diseases	1	1
Infectious diseases	2	2
Chagasic megacolon	2	2
Cardiovascular diseases	9	9
Respiratory diseases	9	9
Neurovascular diseases	16	16
Cancer	29	29
Neurodegenerative diseases	32	32
Total:	100	

Regarding the interventions of the HCS team, guidelines for patient care predominated when compared with other forms of care, as indicated in Figure 1.

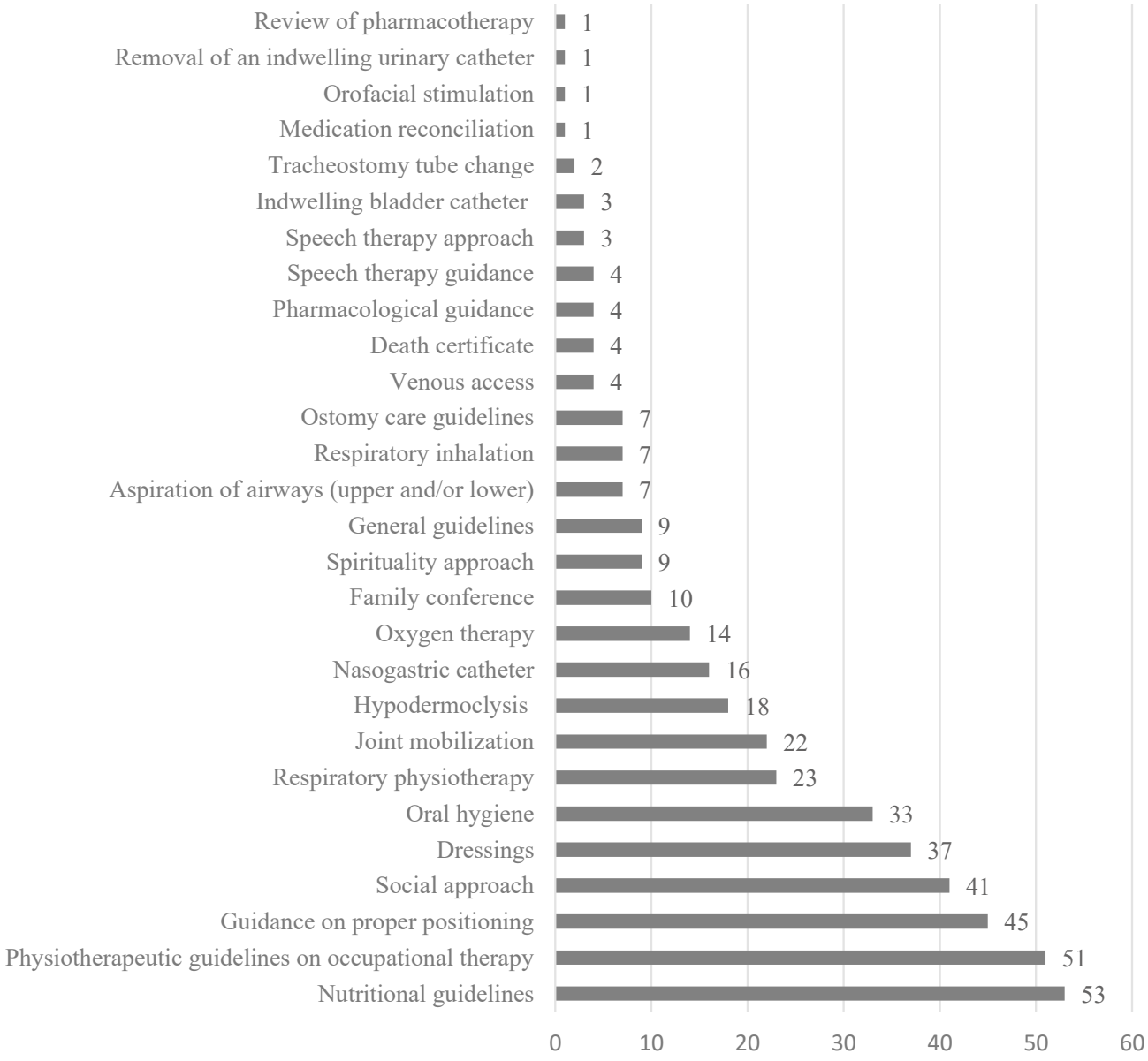

Figure 1. Interventions of the team of Home Care Service of Divinópolis-MG in patients eligible for palliative care.

Data relating to the symptoms presented, as well as the interventions undertaken and their effectiveness, are detailed in Table 2. On the basis of the description of these manifestations in the medical records, 23 were treated ineffectively and 54 effectively, and 22 did not receive treatment by the HCS team.

Regarding the reason for the discharge of patients treated by the HCS, the data are presented in Figure 2.

Table 2. Symptoms presented, treatment and effectiveness of treatment of patients treated by the Home Care Service eligible for palliative care in Divinópolis-MG.

Symptom presented	Treatment	Effectiveness	%
	Treated	Ineffective	20
Anxiety and depression	Treated	Effective	40
	Not treated		40
	Treated	Ineffective	50
Cachexia	Treated	Effective	20
	Not treated		30
	Treated	Ineffective	20
Constipation	Treated	Effective	60
	Not treated		20
	Treated	Ineffective	0
Diarrhea	Treated	Effective	100
	Not treated		0
	Treated	Ineffective	0
Dysphagia	Treated	Effective	100
	Not treated		0
	Treated	Ineffective	21
Dyspnea	Treated	Effective	53
	Not treated		26
	Treated	Ineffective	33
Pain	Treated	Effective	60
	Not treated		9
	Treated	Ineffective	0
Delirium	Treated	Effective	100
	Not treated		0
	Treated	Ineffective	0
Fatigue	Treated	Effective	67
	Not treated		33
	Treated	Ineffective	29
Cough	Treated	Effective	29
	Not treated		42
	Treated	Ineffective	22
Nausea and vomiting	Treated	Effective	44
	Not treated		34
	Treated	Ineffective	20
Pressure injury	Treated	Effective	80
	Not treated		0

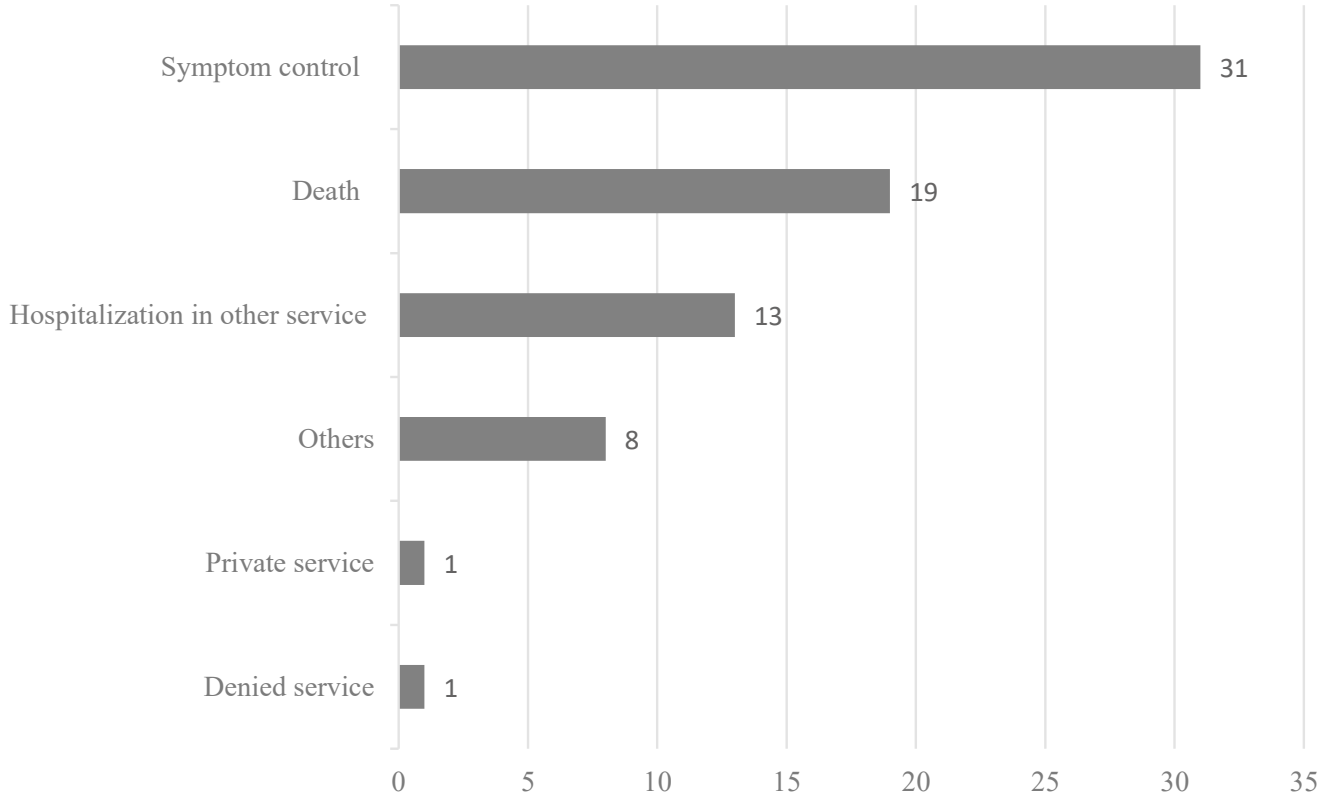

Figure 2. Reason for discharge of patients treated by Home Care Service eligible for palliative care in Divinópolis-MG.

DISCUSSION

PC in Brazil is still at an early stage, and health services, in general, are considered weak in offering a satisfactory approach to patients eligible for PC. In part, this is because of the lack of training of the health team, lack of knowledge of the eligibility criteria for PC[4] and the limited availability of morphine.[18] Furthermore, it is important to point out the difficulties faced by Family Health Strategy in providing active care to patients eligible for PC, because of common challenges, such as underfunding, poor structuring of the health care network and inadequate infrastructure.[6,9,13] In many cases, the support of home care teams is essential for the adequate provision of this type of care.

The data collected reveals an average age of 67 years among the users served. This value differs from other studies that addressed primary health care in Brazil and PC, in which the average age of patients ranged from 78[16] to 47[19] years. In these surveys, the sample was made up of users from 3 basic health units in Londrina, who were submitted to the Palliative Care Screening Tool and obtained 4 or more points,[16] in addition to patients from 14 health units in the city of São Paulo - who had fecal and urinary incontinence.[19]

With regard to the causes of diseases, similar to this study, the literature points to neurodegenerative diseases, cancer and cerebrovascular diseases as the most common.[16,19] It is important to note that, in the case of oncological conditions, many patients are still predominantly hospitalized.[16]

Regarding the interventions by the Divinópolis HCS team in patients under PC, a wide variety were observed. This is in line with the objectives of HCS, where its aim is to provide comprehensive and multidisciplinary care to patients.[14] The most frequent activities included nutritional guidance, physiotherapy

and occupational therapy, as well as guidance on proper positioning. These activities are aligned with the fundamental principles of HCS, which include training patient caregivers, individualizing the care process and embracing families' needs.[14]

The multidisciplinary format plays a crucial role in the provision of PC, aiming to address the diverse needs of patients.[20,21] Multidisciplinarity is also essential for the effective organization of home care.[14] Therefore, it is relevant to highlight the diversity of actions identified in this study, carried out by different professionals from the HCS team. This helps to reduce fragmentation of assistance.[14]

The actions described, carried out by professionals from the home care teams, are related to the criteria for the inclusion of patients in this service.[22] The need for PCs in itself is an indication for this service.[22] In addition, several interventions specific to the teams' responsibilities of home care were carried out, nutritional care, care with ostomies and tubes, administration of medications through hypodermoclysis, changing intravenous accesses, application of dressings, aspiration of airways, changing tracheostomy tubes and the issuance of certificates of death, among others.[22]

Regarding the most common symptoms presented by patients, there was a higher prevalence of dyspnea, followed by pain, constipation and cachexia. In contrast, a comprehensive review carried out between 2015 and 2019 identified pain, nausea/vomiting, dyspnea and fatigue as the most common symptoms among patients in oncological PC in home care.[23] It is important to note that the population under PC served by the Divinópolis HCS team was not limited to cancer patients.

Mood disorders also play an important role in PC, since the presence of depression in these patients is associated with several challenges, such as disability, low adherence to treatment, difficulty in managing physical symptoms and worsening prognosis.[24] However, this study identified only 10 patients with complaints of anxiety/depression, suggesting that the real incidence of these diseases in this group may be underestimated. This may be due to cognitive impairment in some patients, limiting the assessment of emotional symptoms.[16]

Diarrhea is not one of the most prevalent manifestations among PC patients, but it is one the various physical symptoms that is a challenging condition that can lead to several complications.[25,26] However, only 2 cases of diarrhea were identified in the sample collected, 3% of the total selected records. This may raise questions about underreporting of this symptom. However, a systematic literature review carried out in Portugal indicates that the prevalence of diarrhea among individuals undergoing PC is 7–10%[25] That said, it is possible to inquire about the difference between the incidence of real diarrhea and that observed in this study.

Pain was identified as the second most frequent symptom in the sample. However, it is worrying that only 33% of patients who presented with pain received effective treatment. This finding is consistent with a comparison between countries of the assessment of the quality of death and dying, carried out in 2021, which points to Brazil as the 3rd worst country in this regard.[4] Accordingly, among the indicators used to come to this conclusion are adequate coordination of care agents and the availability of opioids for pain relief.[4]

On the other hand, the approach to some clinical manifestations was effective in the majority of cases identified. This included effective treatment of delirium, dysphagia, diarrhea and pressure injuries. These improvements were in line with the interventions of the home care team, such as nutritional guidance and dressing care, among others.

The main reason for the discharge of patients treated by the Divinópolis HCS team was symptom control, accounting for 43% of the causes of discharge. This indicates the effectiveness of this service

in controlling patients' symptoms. Furthermore, it is important to the number of discharges related to hospitalization in other services, suggesting the need for better coordination between hospitals and home care to manage situations that cannot be treated at home.

However, it is important to recognize some limitations of this study. Data collection was based on secondary records, which may subject the information to individual variations by the professionals responsible for each record. Furthermore, data were collected from different professionals at different times and contexts, which may introduce some variability. Finally, the study covered data from 72 patients from a single city in the midwestern Minas Gerais, which may limit the generalization of the results to the entire country.

The results of this study highlight the service capacity and resolution of the home care and primary health care teams in managing patients under PC, highlighting their potential to positively impact the reality of PC in the national scenario. However, to further improve this type of care, research is needed to map the profile of care provided to promote the development of public policies aimed at the country's needs.

CONCLUSION

Analysis of the profile of care provided by the Divinópolis HCS revealed that the mean age of patients treated was 67 years old, with a predominance of female patients. Furthermore, it was observed that the majority of care was directed to patients affected by neurodegenerative diseases. The service demonstrated its ability to control symptoms, representing 43% of discharges. However, difficulties in the effective management of pain, cachexia and cough were also identified.

Knowledge of the reality of care provided in this type of care is essential to for the development and improvement of public health policies. These policies must be based on scientific evidence obtained in the country. Understanding the service profile also helps managers and health professionals in creating training mechanisms and defining service flows aimed at the population that uses the service. Furthermore, it allows the identification of strengths and weaknesses in the service provided.

The results of this study highlight the importance of strengthening home care as an approach to helping PC patients, especially due to its ability to identify and treat symptoms with a high prevalence in these patients. It is essential to invest in the technical training of the team and in the availability of adequate pharmacological treatment to improve the quality of care. Finally, the need to carry out new studies to identify the profile of these services is emphasized to obtain a more comprehensive understanding of the national scenario of care in this modality.

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CONFLICT OF INTERESTS

Nothing to declare.

AUTHORS' CONTRIBUTIONS

AES: Conceptualization, Data curation, Formal analysis; Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – Original draft, Writing – review & editing. VLM: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – Original draft, Writing – review & editing. MAG: Data curation, Formal analysis, Investigation, Methodology, Resources, Visualization, Writing – Original draft, Writing – review & editing. TBES: Data curation, Formal analysis, Investigation, Methodology, Resources, Visualization, Writing – Original draft, Writing – review & editing. LCS: Data curation, Formal analysis, Investigation, Resources, Visualization.

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